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Chapter 7

Lay and peer
counsellors to reduce
leprosy-related
stigma – lessons
learnt in Cirebon,
Indonesia

“I am not shy... so I don't have leprosy, right?”

Abstract

Objective: Counselling has been identified as a promising strategy to reduce stigma. Lay and peer counsellors have provided counselling in various fields, but this has not yet been studied in the field of leprosy. The SARI project in Cirebon District, Indonesia took up this endeavour. This chapter describes the initial experiences based on the perspectives of the lay and peer counsellors and aims to provide lessons learnt for future initiatives.

Methods: The selection of lay and peer counsellors was based upon pre-defined criteria such as completed junior high school and level of confidence. This study draws on the notes of seven monitoring and evaluation meetings and 21 group discussions the main researcher facilitated with the lay and peer counsellors and the notes written by the lay and peer counsellors on the sessions with their clients.

Results: In total, 198 people affected by leprosy were offered counselling by the 11 lay and 12 peer counsellors; 145 accepted this offer. The other 53 either did not need counselling or did not want to participate, for example, due to worries about disclosure. Effective communication skills such as listening and asking effective questions were important, but also difficult to acquire for the lay and peer counsellors. Sharing personal experiences was highly appreciated by clients and stimulated a deepened reflection.

Conclusion: Challenges related to concealment and effective skills exist, but some people affected by leprosy and others can become effective counsellors making it at the outset a challenging but nevertheless promising intervention.

7.1 Introduction

How can we reduce leprosy-related stigma and its impact? Can something so deeply embedded in how people think and act be changed at all? And if so, who should change first, people at the receiving end of stigma or those who stigmatize. And finally, who wants and is able to bring about this change? In this chapter we describe the process of implementing a promising, new approach to leprosy-related stigma namely lay and peer counselling.

In the review of strategies to reduce stigma Heijnders and van der Meij (2006) conclude that counselling interventions which concentrate on the individual and community level are among the most promising strategies. Counselling is defined by Yeo (1993) as a collaborative process in which the counsellor or psychologist facilitates the expansion of people's view of life; enlarges their repertoire of coping resources; and enables them to make choices for change in themselves, the situation, and the environment without

destructive consequences to the self or to others. Several studies have shown that counselling as a stigma reduction strategy is effective in the field of HIV/AIDS, stroke, mental health and leprosy (Evans et al. 1988; Floyd-Richard & Gurung 2000; Corrigan & Calabrese 2005; Hall & Tarrier 2003; Chan et al. 2005). It is thus possible to change something so deeply embedded as stigma, answering the first two questions posed above.

Perhaps even more relevant are some of the other conclusions of Heijnders and van der Meij. According to them, interventions should aim first at empowering affected persons who then can take an active role in stigma reduction (Heijnders & van der Meij 2006). From these conclusions we can take two points. First, it provides a possible answer to the “who should change first” question, being people affected by leprosy. Second, it states that empowered affected people can take an active role in stigma reduction, although, as noted earlier in their conclusion, they should not carry the burden alone. This means that the final question of who wants and is able to bring about this change in stigma, can be partly answered: empowered people affected by leprosy can become agents of change in their communities.

So how can people affected by leprosy and others be involved in a counselling intervention? An interesting development is the training and involvement of lay counsellors. Lay counsellors do not have a professional or academic counselling qualification, but have acquired a basic training in communication skills. Lay counsellors may be staff from non-governmental organisations, DPOs, or health workers, but may also be peers. The term *peer counsellor* is used to refer to lay counsellors who themselves share a personal experience with the client, for example by having the same disease, condition or disability. To our knowledge, lay and peer counsellors have been sporadically involved in the field of leprosy, but this has not yet been formally studied. The aim of this chapter is to draw out lessons from a pioneering study of involving lay and peer counsellors in a leprosy oriented stigma reduction project, the SARI project in Cirebon District, Indonesia. Specific questions addressed are: what challenges emerge in the different counselling phases: beginning, middle and end phase? And, to what extent are the lay and peer counsellors in the SARI project effective counsellors?

First, we will briefly discuss current experiences related to counselling in the field of leprosy, introduce the SARI project and describe the counselling intervention in more detail. In the Results section of this chapter we describe the process of the counselling work starting with establishing the first contact with the client and concluding with the final session. This chapter does not focus on the development of the counselling module, the selection and training of lay and peer counsellors or on the clients’ perspectives. These will be reported elsewhere.

7.2 Counselling for stigma reduction in the field of leprosy

Stigma is a complex construct. It is often described as an undesirable or discrediting

attribute (Goffman 1963), but has several other definitions that are more comprehensive. Weiss describes health related stigma as “a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group [identified with a particular health problem]” (Weiss et al. 2006:280). In comparison, Link and Phelan define stigma as “the co-occurrence of its components – labelling, stereotyping, separation, status loss, and discrimination” – and further indicate that for stigmatization to occur, power must be exercised (Link & Phelan 2001:363). Both these definitions show that the concept of stigma consists of several interrelated components that jointly influence the life of a person affected.

Counselling can target some of these components. The most important resource available in the field of leprosy is a guide on lay counselling produced by ILEP (2011a). In addition the authors are aware of two studies that address counselling in the field of leprosy (Floyd-Richard & Gurung 2000; Thakor & Murthy 2004). We summarize the key points from these sources. First, an effective counsellor has, according to the ILEP guide, “a combination of attitudes and personal qualities, skills, and knowledge of the health condition, the cultural/social context, and good ethics” (ILEPa 2011:10). Attitudes and personal qualities include empathy, non-judgemental, respect, intent to empower and self-awareness. Skills include listening, observing, non-verbal communication, asking effective questions, reflecting and handling emotions. Second, the counselling process is divided in three distinct phases in the ILEP guide. These are the beginning, in which a safe and private setting is created and rapport is built, a middle phase, characterized by listening, observing, identifying needs, setting goals and stimulating actions, and an end phase with a gradual phasing out (ILEP 2011a). Third, the ILEP guide notes that although counselling focuses on the individual it can be valuable to initiate family and group counselling. Thakor and Murthy (2004) also mention these two groups and an example of group counselling is described in the study of Floyd-Richard & Gurung (2000). Fourth, Thakor and Murthy (2004) note that education is key to overcoming stigma but Floyd-Richard and Gurung (2000) critically add that health education alone will not heal stigma. Key messages include, according to Thakor and Murthy (2004), that leprosy is curable, is caused by bacteria (not a sin or curse), that deformity does not mean a person still has the disease and that affected people can live completely normal lives. Fifth, the value of peers is mentioned. The ILEP guides describes peer counsellors as people “who themselves have personal experience of health-related stigma and have come to terms with the challenges it brings” (ILEP 2011a:6). Floyd-Richards and Gurung (2000) refer to a mentor who has gone through the changes him or herself. Some other points relate to the importance of support and continuing training and personal development for the counsellors, counselling ethics, in particular confidentiality, and the importance of a referral system (ILEP 2011a). Based on these resources and others (paper in progress) the counselling intervention was developed as described below.

The SARI project aims to assess the impact of three interventions to reduce stigma in and against people affected by leprosy in Cirebon, Indonesia. The three interventions are: counselling, establishing 'contact' between people affected by leprosy and community members, and socio-economic development through activities such as micro-credit. The project is executed by the SARI team, which is an inclusive team in the sense that people with disabilities and affected by leprosy are part of the SARI team (either as researchers or as research-assistants). In 2011, a mixed-methods study was executed to describe the baseline situation with regard to leprosy-related stigma and in 2014 an end survey will be executed to assess the impact of the interventions. The project is also participatory as persons affected by leprosy and other key persons were actively involved in the design and implementation of the activities.

The counselling intervention aims to decrease stigma and reduce the negative psychological effects of stigma in people affected by leprosy by helping them to have a positive image of themselves, build their knowledge of leprosy, disability and human rights, increase self-awareness, self-confidence and self-advocacy to fulfil their rights and needs. Lay and peer counsellors are the counselling providers. In this study an effective lay or peer counsellor is characterized as a person who is confident to meet and communicate with clients and their families, is able to create a friendly atmosphere, has a positive attitude and has personal experience of the disease or has a connection with people affected by leprosy. The lay or peer counsellor uses active listening, showing empathy and trying to understand the client, and asks probing and reflective questions in their conversation with the clients. An effective counsellor also has knowledge about leprosy, disability and human rights. He or she uses these knowledge and skills to motivate and empower the clients to be self-confident in what they do.

Nine components can be identified in the design and implementation of the counselling intervention:

1. An exploratory study was executed by the four researchers and 10 RAs of the SARI project to understand the everyday experiences of people affected by leprosy and to receive input for the counselling intervention (May 2011 – November 2011).
2. A short 3-day training on the basics of counselling was provided to the RAs of the SARI project by a qualified counsellor who has more than 10 years experience (December 2011).
3. A pilot was executed to assess the need of clients, to test different types of counselling (individual, family, group), assess the approximate duration of each type of counselling and decide on the number of sessions needed. During the pilot 62 persons affected by leprosy received counselling from Mimi Lusli (ML) (PhD student SARI project) assisted by the RAs. The RAs of the SARI project selected clients for the pilot who had potential to become peer counsellors. From 274 people affected by leprosy who participated in the baseline and lived in the counselling area they selected 62 clients based on criteria such as: completed junior high school; confidence to meet people; and communication skills. In addition, the counsellor also

selected potential candidates for the lay and peer counselling training (January – April 2012).

4. Design of the SARI counselling module in which the content for five counselling sessions, including individual, group and family counselling was developed (October 2011 – April 2012).
5. The first training course for lay and peer counselling was given to the RAs of the SARI project and previous clients of the pilot. The aim of the training was to build capacity to be a lay or peer counsellor by developing basic counselling skills and attitudes (such as listening, probing, empathy, advocacy) and by increasing knowledge and awareness. The content was built around four topics; leprosy, stigma, counselling and rights. The participants theoretically and practically learned about how to facilitate counselling during 14 days of training (4 hours of training per day, so 56 hours in total). Interactive training methods were used and self-study and an assignment were required (practicing in providing counselling for a minimum of 10 hours to friends or family) (April – May 2012).
6. Start of the counselling provided by the lay and peer counsellors from the first training, in teams of three. The participants of the baseline study living in the counselling intervention area and newly diagnosed persons in these areas could potentially become counselling clients. Information about which persons are affected by leprosy and their addresses were provided by the leprosy workers at the CHCs. They were visited at their homes. Typically, five counselling sessions were offered: two individual, one family, two group. There was continuous supervision through group meetings and team discussions to improve the counselling skills and overall capacity of the lay and peer counsellors. These were organized on a monthly basis (June 2012).
7. A second training course for lay and peer counsellors was organised to increase the number of lay and peer counsellors. Minor changes in the content were made including more attention to practice. The newly trained lay and peer counsellors selected from their client group people affected by leprosy for the second course, based on the same criteria. In addition, SARI decided to work more closely together with a local DPO. Leprosy is one of the causes of impairments and disability and in order to increase the chance of sustainability of the counselling intervention a close collaboration seemed beneficial. Some disabled members of this DPO were also selected for the second training. For similar reasons, 14 leprosy workers from the CHCs joined the training. The skills they gained during the training can be used in their daily work but they did not become lay counsellors of the SARI project (August 2012).
8. Second training course of lay and peer counsellors, same as before (September – October 2012).
9. The newly trained lay and peer counsellors joined the group of existing lay and peer counsellors. Together the lay and peer counsellors offered counselling to 198 clients and provided counselling to 145 clients (June 2012 – March 2013).

7.3 Methods

This study took place in Cirebon District which is located in the province of West Java near the provincial border with Central Java. Due to its location, people in Cirebon speak different dialects and have absorbed influences from different religions and cultures. The counselling intervention is implemented in 15 sub-districts.

This study is an exploration of involving lay and peer counsellors in the reduction of stigma and its impact in the field of leprosy. It is based on the perspectives of the lay and peer counsellors of the SARI project. The data was collected between April 2012 and March 2013. Demographic information such as age, education, marital status, religion, profession of the lay and peer counsellors was collected by filling in a short questionnaire. This was already done during the lay and peer counselling training. The first author wrote notes on seven monitoring and evaluation meetings, each lasting on average three hours, in which all the lay and peer counsellors together shared experiences and difficulties from the field, reflected on their skills and attitudes and discussed clients' stories. Notes were also taken of 21 team discussions in which small teams of three lay and peer counsellors had in-depth discussions and reflections on their work, skills and attitudes. These also lasted about 3 hours each. During the meetings and workshops lay and peer counsellors narrated the conversations that had taken place with the clients in the field. These experiences are presented in the results section. In addition, the lay and peer counsellors were instructed to write notes on the same day as the counselling session in notebooks or directly in a Word file on clients' responses to the counselling, difficulties in providing the counselling, the team work and on meaningful experiences while facilitating counselling. Sections from these notebooks are also presented in the Results section. All notes were written in *Bahasa Indonesia* and analyzed by my colleague ML. Based on these notes and her own observations she assessed whether the lay and peer counsellors were or became effective counsellors as defined earlier. She read and re-read the notes many times to find themes and patterns. She then categorized similar experiences, issues and phenomena, discussed these with the team and drew out lessons learnt.

7.3.1 Ethical considerations

Permission for the study was given by the relevant government offices and by the Ethics Committee of Atma Jaya University, Jakarta. In the SARI project most people affected by leprosy were met for the first time at the CHCs during the baseline study. They were asked whether they would be interested to join the SARI project as a participant. If they answered positively, they were visited at home. Some others were visited directly at home. Confidentiality was key, so the SARI team discussed the leprosy status of the person with nobody except with the person themselves. If a person affected did not want to join the counselling intervention they were not visited again. If family members or neighbours asked questions they were given an evasive answer. The team rationalized that one visit by one or two persons unknown in the neighbourhood would not create suspicion, but that repeated visits could give rise to questions. Written consent

to participate in this study was obtained from individual clients and lay and peer counsellors. Sustainability of the intervention after the SARI project is concluded was considered important, hence our collaboration with a local DPO, CHCs and the DHO.

7.4 Results

7.4.1 Introducing the lay and peer counsellors of the SARI project

In total, 27 people started the lay and peer counselling training with the intention to become lay or peer counsellors. Four decided to resign during the training for different reasons; pregnancy, job opportunity, realisation there were no financial benefits (although this was clearly mentioned before the start of the training) and because of the reservations of a spouse who was afraid she would be excluded if neighbours found out about the leprosy history of her husband. Table 7.1 provides the demographic information of the 11 lay counsellors (six physically or visually disabled and five non-disabled) and 12 peer counsellors (those affected by leprosy) of the SARI project.

All peer counsellors had finished the MDT and hence were cured from leprosy. Three have a leprosy-related impairment. In total eight, are RAs of the SARI project who have received more training on leprosy, CBR and social research compared to others. The figures clearly illustrate the diversity of the group in variables such as age, education, profession and involvement in a DPO. It also shows that in March 2013, 20 lay and peer counsellors were still active; two passed away and one person found a permanent job that he could not combine with his peer counselling work.

7.4.2 Beginning phase: to create a safe and private setting

During or after the first meeting of the lay or peer counsellor and the client, the client will determine whether he or she will start the counselling process. Hence, the first meeting is important. Visiting potential clients for the first time at their homes was a new activity for most of the lay and peer counsellors. During the meetings and group discussions physically disabled lay counsellors reported that making the first contact and encouraging potential clients to participate in the counselling intervention was a challenge for them. Some of the potential clients appeared to have suspicions and assumptions about disabled people. Some clients assumed that the disabled person was at their house to ask for a donation. The following field experience was shared by a lay counsellor during a group discussion:

Lay counsellor with physical disability: *Hi, good afternoon. May I have some time?*

Client: *Sorry, are you debt collector? Are you here for a donation? Are you salesman?*

Lay counsellor: *Can I introduce myself first, my name is ... and I am one of the lay counsellors at SARI project*

Client: *What? You are a person with a physical disability, why do you want to meet me?*

(Group discussion notes 12)

Table 7.1

Demographic information of lay and peer counsellors (n=23)

Demographic characteristic		Number (%)
Sex	Male	15 (65)
	Female	8 (35)
Age years	18 - 25	8 (35)
	26 - 35	9 (39)
	36 - 45	6 (26)
Religion; Muslim		23 (100)
Marital status	Married	14 (61)
	Single	8 (35)
	Widower	1 (4)
Education	Elementary school	7 (30)
	Junior High School	5 (22)
	Senior High School	6 (26)
	Higher education/university (+ those attending)	5 (22)
Profession	Involved in the SARI project as RA since 2011 (received training on CBR and social research)	8 (35)
	Other job e.g. housewife, farmer, teacher, running small business, repairing mobile phones, handicraft activities	14 (61)
	Jobless	1 (4)
Involved in activities of a DPO in Cirebon		15 (65)
Disability or leprosy	With a physical disability due to polio, car accident or burns	5 (22)
	With visual impairment	1 (4)
	Affected by leprosy (with leprosy-related impairment)	12 (52) 3 (13)
Compensation for counselling work	Paid (RAs)	8 (35)
	Unpaid (compensation for travel expenses only)	15 (65)
Key person in community e.g. religious leader, community leader, teacher, source of information for neighbours		12 (52)
Still active as lay or peer counsellor in March 2013		20 (87)

Potential clients of peer counsellors affected by leprosy were, in contrast, generally willing to discuss the possibilities of joining the counselling intervention when they heard that the counsellor was a person affected by leprosy, as shown by this section from the notebook of a peer counsellor:

In the beginning, I found it difficult [to encourage the client to start counselling] but after the client knew I have been cured of leprosy, he changes his attitude, he does

not see me as a stranger, but we can enjoy having a conversation. (Notes Lay or Peer Counsellor (LPC) 16)

In total 53 persons affected by leprosy out of 198 (27%) that were approached by the lay and peer counsellors did not see a need to start the counselling. In one case, a request was made for a lay or peer counsellor of the same sex by the husband of the client. Of these 53 people, 14 had been cured of leprosy for a long time, had no visible signs and led an everyday life without stigma. Eighteen did not want to start counselling because it did not offer any direct material or financial benefit, such as food or money, to them. Twenty-one people decided not to start the counselling because they were afraid it would create or increase stigma from the community or family. However, this does not mean that all those who concealed their illness decided not to start counselling, as some (14 in total) saw the benefits of counselling and decided to go for it. The perceived need for counselling was not related to the person's treatment status (on treatment or cured) or impairment status (with or without impairment).

7.4.3 Middle phase: with individual, family and group counselling

Counselling skills

The notes of the meetings and team discussions show that applying counselling skills during the individual, family and group counselling sessions was challenging for the lay and peer counsellors. This became apparent to them during the first sessions with the clients. For instance, one peer counsellor told during a team discussion (notes meeting 5) how a client felt insulted and humiliated, because the counsellor assumed too quickly that the client could not read. Peer counsellors had more difficulty with the counselling skills of listening and probing than the lay counsellors. Peer counsellors preferred to talk and share more instantly their knowledge and experiences, whereas for lay counsellors the skills of listening and probing developed naturally as they wanted to first understand the characteristics of the client.

In order to improve counselling skills, the problems of counsellors making assumptions were addressed during the next meeting with all lay and peer counsellors. Over time, the lay and peer counsellors increasingly realized that clients preferred to be listened to compared to being advised, as this increased the confidence of the client in the conversation. In addition, they noted that asking questions deepened the reflection of clients. Consequently, the lay and peer counsellors realized they needed to enhance their counselling skills and several managed to do this. For example, one of the peer counsellors had a client who was losing his vision due to leprosy and experienced sadness and seemed depressed. After listening to the client, the peer counsellor explained the importance of self-care and motivated the client to use glasses. However, the peer counsellor observed that the client seemed more stressed than before. After asking questions and listening some more, the peer counsellor learned that the client did not want others to know he was losing his vision due to leprosy and thought that by wearing glasses others around him would know and stigmatize him. This information helped the

peer counsellor address the client differently. Instead of providing information, the peer counsellor encouraged the client to reflect on the use of glasses and the client started to perceive glasses as a protective tool, in contrast to a tool that would create stigma. By applying a combination of skills, such as listening, asking effective question, observing, motivating and providing information, a change was brought about (Notes LPC 8).

By March 2013, the first author had assessed the skills of the counsellors. She found that the counselling skills of nine lay and peer counsellors could be described as effective, while the counselling skills of the other fourteen counsellors were assessed as weak and still in need of improvement. What are the common characteristics of the lay and peer counsellors in these two groups? Both groups are mixed in terms of demographics: men and women, different ages and different levels of education. Of the nine effective lay and peer counsellors, three are peer counsellors and six are lay counsellors. Of the eight RAs, five became effective lay counsellors but three did not. The most likely distinguishing factor was that many of the lay and peer counsellors with effective counselling skills had more experience and active involvement with community activities in the past. For instance, one young peer counsellor helped organize social activities at his school. Another, a lay counsellor with a physical disability, helped disabled people organize themselves, and yet another lay counsellor is a religious leader and therefore was used to working with people.

Enhancing knowledge

Providing basic knowledge on the disease leprosy turned out to be an important element of the counselling sessions. Most persons affected by leprosy had a lack of basic knowledge, for example, related to the cause of the disease and mode of transmission. Based on the meeting and group discussion notes again the difference in the quality of the counselling skills came to the foreground. Some of the counsellors simply provided information to the clients. For instance, a peer counsellor met a client, asked a question and waited for the client's answer. Even though the answer of the client was an unexpected answer and required further probing, she just asked another question without making a link to her client's situation or client's previous answer. The nine lay and peer counsellors, whose counselling had been assessed as effective, agreed amongst each other that they did not just give information, but helped the clients thoroughly process the information and its implications (notes meeting 2). This was seen as an effective strategy and this management of information was therefore given extra attention during meetings and team discussions.

Peer counsellors seemed to be effective in sharing knowledge because of the credibility gained from their personal experience with the disease. This is illustrated by the following story from the field shared during a group discussion. The peer counsellor told the clients during a group counselling:

Last time, I was an affected person like you. I thought I had this disease because of

curse and magic. After I participated in SARI training on lay and peer counselling, I get knowledge on what leprosy is. It [my understanding] is totally wrong, it is because of a bacteria. Not a curse and not magic. Knowledge on leprosy made me aware and understand that leprosy can be cured and that it is not easy to transmit to people. I am now here sharing my knowledge to you. What do you think? (Notes group discussion 11)

There were similar stories from female peer counsellors and pregnant clients who worried about transmission of the disease.

She [my client] was really worried because of her pregnancy. I listened to her worries. Her understanding is that her disease is a genetic disease and could transmit to her baby. She was thinking about having an abortion. I gave her information on the cause of leprosy. That is not genetic disease, but because of a bacterium. The knowledge that she got from me helped her think more positively, reduced her readiness to have an abortion and she made a self-commitment to keep her pregnancy. (Notes LPC 8)

Sharing (personal) experiences related to stigma: Peer counsellors have been through similar experiences with stigma as their clients. Sharing these experiences helped the clients realize they are not alone with their disease, increased trust further, stimulated reflection, and helped the clients develop a positive self-image. One example from a family counselling session:

Peer counsellor: I am a person affected by leprosy like you, but I could not just stay with no work. I am not an individual human being, I am part of my family and community, and I do not want to be a burden for them. With my health condition, I am not an ill person forever and ever, I have been cured so it is time for me to go back to work to earn money for myself and for my family. (Notes meeting 6)

The physically disabled lay counsellors experienced stigma similarly to persons affected by leprosy (Lusli et al. 2015). When they interacted with clients this parallel strongly supported their counselling work. Often they had more experiences of impairments and disability aids which allowed them to share different experiences. One example comes from an individual counselling session:

Lay counsellor: It seems, you are a very surprised to see me?

Client: Yes, I am wondering, with your impairment, are you not afraid to be stigmatized by the community when coming to my house?

Lay counsellor: May I say that you seem to feel stigmatized by the community when you go out? According to you, what make communities stigmatize you?

Client: I think twice if I want to go out ... Communities around me stigmatize and look at my crooked fingers due to leprosy.

“I am not shy... so I don’t have leprosy, right?”

Lay counsellor: Look my fingers, same with your fingers. Crooked fingers because of burns, but it does not limit me to go out, to meet people, to work , earn money and have opportunities, and I can get all of those things within the community. Those are my rights! If people look at me, I take initiative to closely contact and introduce myself by shaking hand with my crooked fingers by this, stigma can be reduced. What do you think? (Notes group discussion 10)

For the five lay counsellors without a disability or leprosy history, sharing personal experiences was different as they have not lived through a similar experience. They, however, shared stories of people affected by leprosy or with a disability that they got to know personally:

I am aware, I am not experiencing leprosy, so when I do counselling, I should bring a successful life story of a person affected by leprosy, it helps to encourage the client to be more confident, to go out and enjoy life with his family and the community. (Notes LPC 5)

Awareness of rights and advocacy

The discussion on rights was an important element of the counselling sessions. Rights are addressed in individual counselling sessions, but they are discussed in more depth during the group counselling sessions. The client’s realisation that they have rights, and that a disease such as leprosy does not change that, has been shown to be powerful. The lay counsellors who are involved in the work of the DPO were already aware of rights and were some steps ahead of the other lay and peer counsellors. Others learned and increased their awareness about rights through training on this issue. The importance of rights resonated closely with their own experience or fitted with the experience of clients, so it was relatively easy to reach the same level as the ones already involved in the work of the DPO. Much experience from the field related to rights, but also this exchange from an individual counselling session is illustrative:

Lay counsellor: Many times, I hear you mention yourself as a suffering person, what makes you suffer? ...

Client: I do not know, I just hear in the health care centre, the health worker explains to me that I suffer from leprosy, I have a spot in my face. ...

Lay counsellor: According to you, can a suffering person work? What do you think about a suffering person?

Client: Crying, feeling sad, doing nothing, not able to work, whimpering in pain

Lay counsellor: Do you like that person?

Client: So I am not a suffering person ..., since I cannot just sit without activities, I want to make my life busy, my rights?

Lay counsellor: Yes you are right; you have rights. (Notes LPC 11)

Diverse needs

During the individual, family and group counselling sessions, clients discussed a variety of needs and struggles. Foremost was their financial situation, but also medical care, continuation of study and participation in social activities. In some cases, the counsellors took an active role and assisted the clients by going beyond providing counselling (e.g. mediation), sometimes using rights as an advocacy tool:

Through counselling I [peer counsellor] got to know that the client needs medical treatment but he is shy, afraid and has little confidence to go to the community health services. Thanks to the peer counsellor who has assisted him [to the CHC] he got medical treatment. (Notes LPC 23)

I successfully helped my client to reclaim her right to go to school again. ... The school did not allow her to go to school. ... She faced stigma at school that made her feel shy and she had no confidence to meet friends and teachers. Through counselling, session by session, I listened to her feelings and thoughts. ... When I asked her if she wanted to go to school, she smiled, and asked me to bring her to meet the headmaster and teachers. After consulting on her health condition with her leprosy officer and her parents, I tried to meet the head master in her school. In the first meeting, I lobbied by giving an explanation of her health condition and asking the school for her opportunities. During the second meeting, I accompanied her to talk with her head master and her teachers. ... The school opened up and changed their mind. They welcomed her back to school. (Notes LPC 5)

There also were needs that went beyond the aims of stigma reduction of the counselling provided by the SARI project. In one case, the client talked about the violent behaviour of her husband towards her. In this case the lay counsellor, who is also a religious leader, was on his own able to make a profound change in his client's life, as shown here:

She openly and freely shared her violence experience to me. She was kicked and hit by her husband for a long time, she kept silent in her heart. ... After 5 sessions of counselling, she said to me "I have faith in you; you made me dare to talk". ... During counselling sessions, I listened to her and clarified information that she gave to me by inquiring more. I strengthened her capacity. My counselling skills and my spiritual experience were useful to help my client show her spirit and confidence living a peaceful life with her husband. (Notes LPC 15)

Another case tells the story of a client who was considering suicide because he felt tired by the medical treatment, visiting hospitals and spending a lot of money without being cured. The counselling motivated him to seek help at the CHC. Supported by his family he went there and started to take his medication routinely again. At the end of the counselling sessions he thanked the lay counsellor for opening his mind and appreciating the treatment from the CHC again. He feels better and is more relaxed in daily

life. In these examples, had the lay counsellors not have been successful, the client would have been referred to a professional counsellor or psychiatrist.

Location and logistics

The distance between clients was one of the challenging factors for the lay and peer counsellors while facilitating counselling in the field. Public transport is available but takes a lot of time and is less frequent after 6 p.m., a time when many clients were at home and preferred to have a counselling appointment. Therefore the availability of motorcycles was important. Flexibility in arranging the time to meet the clients was shown to be important for both the lay and peer counsellors and clients. Lay and peer counsellors have said that they value such flexibility as it, for example, can allow them to be both a teacher in a school and a lay or peer counsellor. Others said they often provide counselling after office hours or on Sundays in order to fit in with the schedule of the clients. However, there were some challenges regarding time management such as clients who preferred to meet more frequently or longer than feasible for the lay and peer counsellors. Two examples:

I have a dilemma, my client asked me to stay longer as she needs friends, she needs to talk, she also needs to be listened to. I do not want to make my client sad, but on the other hand, I should be back home as soon as possible, otherwise my husband will be angry with me and I do not have time to take care of our child at home. (Notes LPC 8)

Today, my client complained to me that I seldom visit her and when I facilitated the counselling I felt ignored by her. (Notes LPC 7)

The lay and peer counsellors reported during the fourth meeting that most clients preferred not to use their house for group counselling. On the one hand, the clients were worried and felt uncomfortable when their house was visited by many new people, especially if they had leprosy-related impairments. This was particularly relevant when the client did not want his or her neighbours to know that he or she currently is or once was affected by leprosy. On the other hand, the clients were eager to have group counselling since they knew from the lay or peer counsellor that in a group they could meet “friends” who have or had the same disease. In search for an alternative location, most clients also refused to use a Community Health Centre for group counselling. For some clients this was due to mistreatment and stigmatisation by health workers. There were, however, also 42 clients who did not mind having the group counselling session in their house, allowing clients from other villages to come to their house.

7.4.4 Ending phase and gradual phasing out

Of the 145 clients that started the counselling provided by the lay and peer counsellors, 56 decided to skip one session or stopped the counselling prematurely. Table 7.2 provides an overview showing how many clients joined which sessions and how many skipped one session or stopped along the way.

Table 7.2

Number of clients who attended counselling sessions from lay and peer counsellors (n=145)

Session	Counselling type	Number of clients
1	Individual counselling	145
2	Individual counselling	145
3	Family counselling	98
4	Group counselling	127
5	Group counselling	89

Several reasons why clients decided to discontinue the counselling were identified by the lay and peer counsellors. First, some clients were rarely at home due to a job in another district or city which made it difficult to commit to the counselling. Second, some family members of clients prevented a continuation of the counselling because they were worried about potential stigma from neighbours, for instance gossiping, that might result in their affected family members being avoided. Third, some clients felt that fewer sessions were enough to suit their needs, for instance their need for information about leprosy. They were “bored” by the conversation due to the repetition of topics. Finally, some clients did not want to continue, because they did not obtain material or financial support. Some clients were embarrassed to talk openly about their wish to stop the counselling, which could be difficult for the lay and peer counsellors as shown by this quote:

We know the client is inside the house, he or she hides and asked family members to say that he or she is not at home ... We wonder why they must lie, we expect that they would like to meet us to receive counselling, we feel disappointed, but we should think from clients' perspective why they did, for us, it is better if the client talks, he or she does not want to be disturbed by receiving a counselling session. (Notes LPC 10)

In total, 69 clients needed and asked for more than five sessions. Mostly individual sessions were added, but for some young people affected, more group counselling was considered beneficial. The number of sessions that were added depended on the individual needs of the client, but were up to 12 sessions in total. A group of women that joined group counselling developed into a handicraft group. Sometimes a different and more long-term relationship was established as illustrated by this quote:

What was particularly meaningful for me, is that when the counselling sessions were finished, my client and I had developed a relationship as friends. When I am out and pass the client's house, I drop by and have a chat with him. (Notes LPC 16)

7.5 Discussion

For several health conditions there is an urgent need for stigma reduction activities (Van Brakel et al. 2012; Cross et al. 2011a). With this study we contribute by describing the initial experiences of a novel strategy in the field of leprosy, namely providing lay and peer counselling. Our findings provide insights on involving lay and peer counsellors in reducing stigma and its impact. Findings come from the whole counselling process: from the first knock on the clients’ door to the conclusion of the counselling. They also depict experiences from various lay and peer counsellors: some affected by leprosy, physically or visually disabled and others neither affected nor disabled. Eight key lessons learnt can be abstracted from our findings and these are compared to the findings of other studies.

First, the initial contact between lay or peer counsellor and client is an important moment as at this point the clients determine whether counselling could be of benefit and hence if they want to start counselling or not. Creating a safe and private setting and building rapport as mentioned in the ILEP guide (2011a) are indeed key. This study showed that encouraging potential clients to participate was the most challenging for lay counsellors with a physical disability due to some initial assumptions about disabled people. To our knowledge very few studies and guidelines address the potential stigmatisation of lay and peer counsellors by possible clients. We would like to underscore the importance of this type of stigmatisation and believe more attention to this is needed. For instance, awareness needs to be raised in the training of lay and peer counsellors and in the work of the supervisor so that the lay and peer counsellors learn how to anticipate and deal appropriately and effectively to this stigmatisation. Interestingly, later on in the counselling process, the disability of counsellors often became an advantage as it helped stir deeper reflection in clients.

Second, this study showed that people affected by leprosy who have concealed their illness often reject the counselling or stop along the way due to a worry about disclosure and possible stigmatisation from family or community members. This is an important finding as these clients are, among others, the persons you would like to reach. They may feel a psychological burden due to the secrecy and have a highly internalized stigma and therefore would most likely benefit from counselling. However, counselling provided at their homes may indeed draw unwanted attention and this could lead to involuntary disclosure, which then could eventually create or increase stigma. One could wonder if the home-based approach fits these clients’ context and if counselling at a more neutral place may be more appropriate. There is a contradiction here, because going out of the house might be another challenge for this group. The study of Baiden et al. (2007) on community acceptance of lay counsellors, also found a fear for stigmatisation and discrimination of clients as a result of disclosure. Likewise, counsellors in a study in Botswana noted that clients’ fear of stigmatization was a barrier to effective counselling (Buwalda et al. 1994). Privacy and guaranteeing confidentiality to avoid stigma due to involuntary disclosure are

extremely important and should be the priority in a counselling intervention, as also noted by Baiden et al. (2007)

Third, sharing knowledge about the disease leprosy, going beyond the simple dissemination of information, was one of the main tasks of the lay and peer counsellors in this study. Peer counsellors seemed to be the most effective as the clients trusted and could relate easily to the information from peers. Other studies have critiqued the focus on education in lay counselling. For example, information-giving and advice were often used as strategies by the counsellors in the study of Dewing et al. (2013), as illustrated by the title of their paper “It’s important that you take your medication everyday okay?” Also Richter et al. (2001) write that HIV counselling services in South Africa are based primarily on an educational model. However, in the context of Cirebon District, the lack of knowledge regarding basic facts about the disease was also described in Peters et al. (2013) and its effect on stigma is important. Information-giving thus remains one of the key activities of the lay and peer counsellors.

Fourth, imparting knowledge is not, however, the most important of the necessary skills for counsellors. These are listening actively and showing empathy, asking effective questions, sometimes in a reflective or challenging manner, and motivating the client to have self-confidence and self-empowerment. After the initial 14 day (56 hours) counselling training, the lay and peer counsellors in this study needed to further enhance their counselling skills in practice. From this study we can learn that developing effective counselling skills (as described earlier) was challenging for the lay and peer counsellors. In particular, peer counsellors had the tendency to start sharing and advising too soon, whereas clients preferred to be listened to rather than to be advised. Through continuous supervision nine out of 23 (39%) managed to develop effective counselling skills over about one year’s time. This number is lower than expected. The first author believes about half of the 14 with current weak counselling skills still have the potential to become effective lay or peer counsellors, but the others will most likely stay at the level they are at right now. We need to emphasize here that this group will still be a valuable resource for leprosy services, even if not as a lay or peer counsellor. That becoming an effective counsellor is challenging is also addressed in the study of Dewing et al. (2013) who evaluated counselling delivered by lay counsellors in Cape Town. They found that the counselling practice was not consistent with the approach to counselling in which they were trained, disregarded its core principles and at times applied inappropriate strategies such as moralising, warning and confrontation. An important implication of ineffective counselling skills of lay and peer counsellors is that clients may reject counselling or not enjoy the counselling they received, for example when the counselling is more a question and answer session than a genuine conversation. Also, if the skills of providing information are weak, the client might be confused by unclear information. This might explain why some clients in this study preferred to stop after the second, third or fourth session. In addition, in this study some clients brought up issues (violence, depression, suicidal thoughts) that were beyond the scope of SARI counselling, so a good referral system as also mentioned in the ILEP Guide (2011) is important.

Fifth, three out of the nine effective counsellors are peer counsellors. They feel a high responsibility towards their peers among others regarding the sharing of knowledge about leprosy. The peer counsellors in the SARI project gained important knowledge about leprosy by joining the project and they are keen to share this knowledge. *“If we do not help our peers, who will?”* one peer counsellors recently said. This responsibility, the lived experience and high trust among clients and peer counsellor increases the potential of peer counsellors compared to lay counsellors. A dedication to their work and a motivation to help people was also found in the study of Sanjana et al. (2009).

Sixth, the training and supervision provided in the SARI project can be described as intense. However, this was certainly needed as still 14 lay and peer counsellors did not manage to become effective counsellors. As several other studies have done, we also underline the need for a long term commitment and good selection (including criteria as experience with community work’ and ‘confidence to meet and interact with people), training in counselling skills and ethics, on-going support and supervision, trainings to review and refresh knowledge and skills of lay counsellors (Msisuka et al. 2011; Sanjana et al. 2009; Dewing et al. 2013).

Seventh, the lay and peer counselling strategy unfortunately does not reach all in need and does not address all needs. Hence, multiple strategies like education, contact, socio-economic development and addressing different sources such as community members, family, and health workers remain needed to reduce leprosy-related stigma further. If there is an interest at national level in implementing a lay or peer counselling intervention, we envision in the Indonesian context that the Ministry of Health creates the capacity at Provincial and District levels to manage these tasks and responsibilities. Sustaining the counselling services over a longer time might mean that people who initially did not dare to engage with counselling may be willing to do so once community stigma has been reduced.

Finally, we believe that more research is needed in this field and recommend that others study specific elements systematically and in-depth such as how the training process could be improved in order to increase the number of effective counsellors, the perspectives of the clients on the counselling and possibilities for its integration with existing structures and organisations. The authors of this chapter are part of the SARI team and the first author of the paper (Mimi Lusli) on which this chapter is based is responsible for the execution of the counselling intervention. This role can provide unique insights, but also lead to bias in writing. Discussions among the SARI team and authors about the findings lead to a more accurate and critical understanding on the role of lay and peer counsellors to reduce stigma in persons affected by leprosy.

7.6 Conclusion

In the first paragraph of this chapter several questions are stated, of which the last one was: “Who wants and is able to bring about the reduction of leprosy-related stigma?”

This chapter has shown that some, but not all, empowered people affected by leprosy can be effective counsellors in their communities. The process of involving lay and peer counsellors in reducing stigma and its impact in the field of leprosy is challenging due to people's desire to conceal their condition and the difficulty of developing effective counselling skills in the counsellors. Observing and analysing the different steps of the lay and peer counselling also showed the great potential of this approach, in particular the credibility of the knowledge and personal experiences lay and even more so peer counsellors can share. We conclude that lay and peer counselling holds much promise as an effective and appropriate strategy for stigma reduction in leprosy.